SATISFACTION IN DEMENTIA AND STROKE CAREGIVERS: A COMPARATIVE STUDY

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Informal caregiving to the elderly is associated with the presence of both difficulties and positive rewards, but the latter have been considered less systematically in gerontological literature. In this cross-sectional study, we compared satisfaction of caregivers of demented (n=70) and stroke patients (n=44) by means of the Carer's Assessment of Satisfaction Index (CASI) and also compared their depression levels. Findings revealed the presence of satisfaction deriving from intrapersonal dynamics (elderly as main beneficiary) and from interpersonal dynamics (caregiver as main beneficiary) in dementia situations, and the presence of satisfaction deriving from intrapersonal dynamics (caregiver as main beneficiary) in stroke situations. Both subgroups of caregivers revealed similar yet significant levels of depression. The need for a better understanding of satisfaction experiences in dementia and stroke caregivers is highlighted.

DESCRIPTORS: personal satisfaction; caregivers; aged; Alzheimer disease; stroke

PERCEPCIÓN DE LA SATISFACCIÓN DE CUIDADORES DE PERSONAS CON DEMENCIA Y DE CUIDADORES DE PERSONAS CON AVC

La prestación informal de cuidados a las personas ancianas está vinculada a la presencia de dificultades y de satisfacciones. Generalmente la literatura gerontológica enfoca los aspectos de la dificultad, sin embargo no le ha dado la misma atención al análisis de la experiencia de la satisfacción. El propósito de este estudio transversal fue comparar la experiencia de satisfacción y de sintomatología depresiva de cuidadores de ancianos con demencia (n=70) y de cuidadores de ancianos con antecedentes de, por lo menos, un AVC (n=44), a través del Índice de Evaluación de la Satisfacción del Cuidador (CASI). Los resultados indican la presencia de sintomatología depresiva en ambos grupos; satisfacción intrapersonal (centrada en el anciano) y interpersonal (centrada en el cuidador) para los cuidadores de ancianos con demencia y, satisfacción intrapersonal (centrada en el cuidador) para los cuidadores de personas con antecedentes de AVC. Se destaca la necesidad de comprender mejor las experiencias de satisfacción en los cuidadores de ancianos con demencia y AVC.

DESCRIPTORES: satisfacción personal; cuidadores; anciano; enfermedad de Alzheimer; Accidente Cerebrovascular

ESTUDO COMPARATIVO: PERCEPÇÃO DA SATISFAÇÃO DE CUIDADORES DE PESSOAS COM DEMÊNCIA E CUIDADORES DE PESSOAS COM AVC

A prestação informal de cuidados a pessoas idosas é vinculada à presença de dificuldades e de satisfação. Enquanto a literatura gerontológica enfoca os aspectos da dificuldade também tem negligenciado a análise da experiência de satisfação. O propósito deste estudo transversal foi comparar a experiência de satisfação e de sintomatologia depressiva de cuidadores de idosos demenciados (n=70) e de cuidadores de idosos com antecedentes de pelo menos um AVC (=44), através do Índice de Avaliação da Satisfação do Cuidador (CASI). Os resultados indicam a presença de sintomatologia depressiva para ambos os grupos, satisfação intrapessoal (centrada no idoso) e interpessoal (centrada no cuidador) para os cuidadores de demenciados e satisfação intrapessoal (centrada no cuidador) para os cuidadores de pessoas com antecedentes de AVC. Destaca-se a necessidade de compreender melhor as experiências de satisfação em cuidadores de idosos com demência e AVC.

DESCRITORES: satisfação pessoal; cuidadores; idoso; doença de Alzheimer; acidente cerebral vascular

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BACKGROUND

Alzheimer's disease and stroke are two of the most common sources of disability in western society that lead to the need for family caregiving; the first one, considered the "century's disease"[1], constitutes a chronic progressive disorder that leads to the most common irreversible dementia among older persons[2]; the second one is an important cause of death and figures among the leading causes of disability around the world[3]. Both conditions comprise a well-known burden and stress for the caregivers[4-5], but few reports have compared those two caregiving situations in what regards the presence of positive rewards and gratifications, such as feeling more useful, feeling needed, feeling good about the self, finding meaning in life or learning new skills.

As the complexities and dynamic nature of caregiving underscore the critical importance of reflecting on both the negative and the positive aspects of the role, and considering that relatively little attention has been paid to satisfaction in caregiving research[6], the aim of the present study is to compare measures of satisfaction and depression in elderly co-resident caregivers of stroke and dementia patients. To define "satisfaction with caring", we considered a theoretical framework[7] that includes three different dimensions: (i) satisfaction deriving from interpersonal dynamics between caregiver and care receiver; (ii) satisfaction deriving from the intrapersonal or intrapsychic orientation of the caregiver and care receiver (intrapersonal dynamics) and; (iii) satisfaction deriving from a desire to promote a positive or avoid a negative outcome in the care receiver (a result of some action). We have also considered these authors' distinction between who mainly benefits from the satisfaction felt - the caregiver or the care receiver[2,7].

METHODS

Sample

The sample comprises two distinct subgroups: 70 caregivers of patients diagnosed with Alzheimer's disease and 44 caregivers of persons who were stroke survivors (either from hemorrhagic or ischemic cerebral vascular accidents). Dementia patients were recruited from a public Psychogeriatric Service in a Psychiatric Hospital and their caregivers were interviewed at the hospital or at their homes. Stroke patients were recruited from a rehabilitation service at a private hospital and interviews were held at their homes. The Ethics Committee of both institutions gave approval for the study.

Table 1 presents the main demographic and background characteristics of each subgroup of caregivers, as well as the specific contexts of care delivery. Significant differences were found between the subgroups in terms of gender (substantially more women in dementia situations), work status (caregivers more likely to be employed in stroke situations) and some dimensions of the context of care (revealing dementia caregivers as the subgroup more likely to provide help on a continuous 24h basis, for a longer period of time and with no secondary help).

Table 1 – Caregiver characteristics and contexts of care by subgroup

Variable	Dementia situations N=70	Stroke situations N=44	p
Caregivers			
Gender n (%)			
Male	11 (15.70)	18 (40.90)	0.005
Female	59 (84.30)	26 (59.10)	
Age, mean (SD)	59,85 (14.17)	61,45 (10.44)	
Educational Level[1], n (%)			
< 4 years	15 (21.40)	12 (27.30)	0.388
4 years	33 (47.10)	15 (34.10)	
> 4 years	22 (31.40)	17 (38.60)	
Work Status, n (%)			
Employed	22 (31.42)	28 (63.63)	<0.001
Retired/unemployed	48 (68.57)	16 (36.36)	
Relationship with care receiver, n (%)			
Spouse	29 (41.42)	10 (22.72)	0.062
Children	30 (42.85)	18 (40.90)	
Others	11 (15.73)	16 (36.38)	
Context of care			
Frequency of help provided, n (%)			
Seldom	4 (5.80)	17 (38.60)	<0.001
Sometimes	10 (14.50)	14 (31.80)	
Often	15 (21.70)	6 (13.60)	
Always	40 (58.00)	7 (15.90)	
Time spent on caregiving, n (%)			
Irregular contact	22 (31.42)	7 (15.90)	0.019
Half-day	19 (27.14)	23 (52.27)	
24 hours/day	29 (41.42)	14 (31.81)	
Duration of caregiving, n (%)			
< 6 months	5 (7.14)	17 (38.63)	<0.001
6 months < 12 months	7 (10.00)	19 (43.18)	
> 12months	58 (82.85)	8 (18.18)	
Secondary caregivers, n (%)			
Inexistent	19 (27.14)	0 (0.00)	<0.001
Professional help	20 (28.57)	24 (54.54)	
Family	31 (44.28)	20 (45.45)	
Domestic aid			
No	58 (82.90)	21 (47.72)	<0.001
Yes	12 (17.10)	23 (52.27)	

1. Number of years of full-time education.

In both subgroups, care receivers were mostly female (58.6% in dementia situations and 66% in stroke situations) and very old (mean age of 78.87, SD=6.9 in dementia situations and 76.04, SD=9.47 in stroke situations). Dependency levels were significantly higher in the demented care receivers.

Data Collection and Instruments

After informed consent to participate in the study was obtained from the caregivers, confidentiality was promised and voluntaries were assured, several instruments were used to assess different aspects of the caregiver's experience. Information comprising demographic and background/contextual variables were obtained through a brief informative questionnaire. The caregiver's sense of satisfaction was examined by the Carer's Assessment of Satisfaction Index (CASI)[8], an instrument that evaluates the caregiver's subjective experience of satisfaction and the extent of satisfaction that is associated to each of these factors. It involves 30 different items associated with the person being cared for (10 items), with the caregiver (12 items), or related to interpersonal dynamics (8 items); when completing the scale, the subjects are asked to indicate whether each item applies providing a great deal of satisfaction (4), applies and provides quite a lot of satisfaction (3), applies but does not provide a source of satisfaction (2), or does not apply to them (1). Caregiver's depression was measured using the Portuguese version of the Centre for Epidemiologic Studies Depression Scale (CES-D)[9], adopting scores of 20 or higher to indicate depression for descriptive purposes. Finally, the patient's disability and dependency were assessed by Lawton's- Index of Instrumental Activities of Daily Living[10].

Data Analysis

Statistical analysis was carried out using SPSS for windows, version 14.0. Comparisons between groups were performed using Mann-Whitney and Kruskal-Wallis tests, as well as Spearman's coefficients, Chi-square analysis and Fisher's exact test for 2 groups. Package r–part of R Program, version 2.4.1 was used for decision tree analysis. Level of significance was set at .05.

RESULTS

As we can see in Table 2, satisfaction with caregiving was found in both subgroups of caregivers, with some significant differences with regard to its source (dynamics) and to the perceived beneficiary of care: in intrapersonal dynamics, stroke caregivers presented higher satisfaction when the caregiver was the main beneficiary of care (20.3; SD=4.2) and dementia caregivers presented higher satisfaction levels when the care receiver was the main beneficiary (6.9, SD=1.3); in interpersonal dynamics, when the caregiver was considered the main beneficiary, dementia caregivers revealed higher satisfaction (7.7, SD=2.5) than stroke caregivers (7.0, SD=2.4). When using the CASI subscales as outcomes in a non-conditional logistic regression model, the adjusted odds ratios showed significant differences between the groups, mainly evidencing principally that stroke caregivers are more likely to derive satisfaction from intrapersonal dynamics with the caregiver as the main beneficiary of care than dementia caregivers (OR 0.7, 95% CI 0.6-0.9).

Table 2 - Caregiver's Satisfaction: Dementia vs. Stroke

CASI sub-scales	Dementia	Stroke	Adjusted odds ratio
	Mean (SD)	Mean (SD)	(95% CI)[1]
Satisfaction derived from interpersonal dynamics - caregiver as main beneficiary	7.7 (2.5)*	7.0 (2.4)	1.4 (1.0-1.8)*
Satisfaction deriving from interpersonal dynamics - person cared for as main beneficiary	10.4 (1.6)	10.5 (1.3)	0.9 (0.6-1.4)
Satisfaction deriving from interpersonal dynamics - mutual benefit	7.9 (2.7)	8.1 (2.3)	0.8 (0.6-1.2)
Satisfaction deriving from intrapersonal dynamics - caregiver as main beneficiary	17.2 (6.2)	20.3 (4.2)**	0.7 (0.6-0.9)**
Satisfaction deriving from intrapersonal dynamics - person cared for as main beneficiary	6.9 (1.3)*	6.5 (1.2)	1.5 (1.0-2.3)*
Satisfaction deriving from intrapersonal dynamics - mutual benefit	14.7 (3.6)	15.3 (3.5)	1.0 (0.8-1.2)
Satisfaction deriving from outcome dynamics - caregiver as main beneficiary	4.4 (2.0)	5.1 (1.7)	0.9 (0.6-1.2)
Satisfaction deriving from outcome dynamics - person cared for as main beneficiary	15.3 (3.7)	15.2 (3.0)	1.1 (0.9-1.3)

[1] Model calculated through non conditional logistic regression and adjusted for all CASI dimensions
*<0.05; **<0.01

As to the presence of depression, though global scores of CES-D revealed to be very similar in both subgroups (indicating the presence of symptoms at clinical level), when considering the four-factor structure of the scale[11], several significant differences were found in "depressive affect", "positive affect" and "interpersonal factors" (see Table 3). When using CES-D factors as outcomes in a non-conditional logistic regression model, the adjusted odds ratios demonstrated that the "positive affect" factor (which includes feeling hopeful about the future, feeling happy or enjoying life) significantly distinguishes stroke caregivers from dementia caregivers (OR 1.3, 95% CI 1.0-1.7) and that "interpersonal" factors (feeling that the other dislikes me or sees me as unfriendly) distinguishes the subgroups in a more significant way, with stroke caregivers presenting more of these depressive symptoms (OR 0.3, 95% CI 0.1-0.4).

Table 3 - Caregiver's Depressive Symptoms: Dementia vs. Stroke

CES-D factors	Dementia Mean (SD)	Stroke Mean (SD)	Adjusted OR 95% CI[1]
Depressive Affect	8.8 (4.8)*	7.5 (2.3)	1.1 (0.9-1.2)
Positive Affect	5.2 (2.7)*	4.3 (1.7)	1.3 (1.0-1.7)*
Somatic and retarded activity	7.0 (4.2)	6.5 (2.2)	1.1 (0.9-1.3)
Interpersonal	0.8 (1.3)	2.5 (1.3)***	0.3 (0.1-0.4)***
Total score	21.9 (10.9)	20.9 (3.9)	

[1] Model calculated through non conditional logistic regression and adjusted for all CES-D factors
*<0.05; **<0.01; ***<0.001

In general, when considering the results of CASI and CES-D, the main differences between the subgroups can be synthesized as follows (see Table 4):

Table 4 - Caregivers of stroke patients and demented patients: main distinctive features

Caregivers of stroke patients	Caregivers of demented patients
	+ Satisfaction derived from interpersonal dynamics - caregiver as main beneficiary (CASI)
+ Satisfaction deriving from intrapersonal dynamics - caregiver as main beneficiary (CASI)	
	+ Satisfaction derived from intrapersonal dynamics - person cared for as main beneficiary (CASI)
+ Depressive symptoms - interpersonal factor (CES-D)	
	+ Depressive symptoms - positive affect factor (CES-D)

DISCUSSION AND CONCLUSION

Caring for another person can be experienced as stressful and burdening but it can also be an important source of positive rewards. One main finding of this study was that a high proportion of caregivers expressed satisfaction, irrespective of the distinction made between the caregiver and the person cared for as the perceived beneficiary of care, and irrespective of the privileged dynamic source of satisfaction (either intrapersonal, interpersonal or outcomes). Another relevant finding was that both subgroups reported that satisfaction is co-existent with depressive symptoms, which were found at a very similar level in both situations.

However, when looking at the subgroups we have considered, two major differences were identified: the first is that, although they both presented sources of satisfaction, suggesting altruistic concern with the welfare of the person cared for (intrapersonal dynamics), dementia caregivers more likely interpreted their satisfaction in the light of the care-receiver's well being, while stroke caregivers rooted their source of satisfaction mostly in the accomplishment of their own efforts, such as fulfilling a sense of duty or showing personal skills (caregiver as main beneficiary of care); secondly, we concluded that dementia caregivers were more likely to derive satisfaction from interpersonal dynamics, especially from receiving appreciation for their efforts (caregiver as the main beneficiary). A potential explanation for these results may rely on the fact that specialized services for Alzheimer's disease patients are not widely available in Portugal[12], which restricts the availability of service options and their quality. In this context, the caregiver's efforts to maintain the care receiver's dignity and keep him/her out of an institution can be highlighted as an important source of satisfaction, along with the social recognition of the caregiver's invaluable associated efforts. Furthermore, in contrast with caregivers of patients with stroke, who abruptly have to cope with a situation of dependency they are not prepared for and may highlight the development of new skills and abilities when identifying sources of satisfaction in the role, dementia caregivers may be less aware of such efforts, attributing greater value to interpersonal dynamics. Some of these results have been partially presented in recent studies on older male caregivers[13] but need further investigation.

Despite the limitations of this study (e.g. sample size and several differences in the constitution of the subgroups), we think that it provides significant implications for nurses and other health professionals with regard to the increased attention needed for satisfaction in caregiving. This article notes that the experience of satisfaction with care can minimize and put the negative experiences associated with care into another perspective. "It is important to consider the family both as a unit of care and a unit to be taken care of"[14]. In a field where there is growing evidence that satisfactions are associated with improved caregiver well-being, we believe that understanding the satisfaction of caring is more than of theoretical interest, and should therefore be included in the assessment of the caregiver's global circumstances. The way the role and its activities are perceived in terms of satisfaction can enrich the caregiver's experience (within its several dynamics) and can be a useful tool for professional interventions. Health professionals have to anticipate the needs of caregivers and foresee the development of personal situations[15]. The CASI instrument has been increasingly used in caregiving studies, providing important reflections for intervention[16-17], but it is still mostly used in dementia situations. We strongly advocate that it should be more used in samples of stroke caregivers, as it can provide important data and tools for nursing professionals in their work with the family's participation in the care receiver's rehabilitation process.

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